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# ‘Global bereavement care after stillbirth – Consensus: The RESPECT Study’

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Synopsis: A modified policy Delphi process established global consensus on eight principles for bereavement care after stillbirth.

## Abstract:

**Objectives:** An estimated 2.6 million stillbirths occurred worldwide in 2015. The bereavement care received by women and their families, however, is often deficient and inconsistent. We sought to develop global consensus on a set of evidence-based core principles for bereavement care after stillbirth.

**Methods:** A modified policy Delphi methodology was used to consult international stakeholders and healthcare workers with experience in stillbirth. Five sequential rounds involved two expert stakeholder meetings and three web-based surveys, including a global web-based survey targeted at healthcare workers in a wide range of settings.

**Results:** The global survey received 236 responses from 26 countries, after which nine principles met a priori criteria for inclusion. The final stakeholder meeting and web-based survey of all participants confirmed consensus on eight core principles.

Highest quality bereavement care should be enabled through training of healthcare staff to reduce stigma and establish respectful care; including acknowledgement and support for grief responses, and provision for physical and psychological needs. Women and families should be supported to make informed choices, including with regard to their future reproductive health.

**Conclusion:** Consensus was established for eight stillbirth bereavement care principles. Further work should explore implementation and involve the voices of women and families globally.

## Introduction:

An estimated 2.6 million stillbirths occurred worldwide in 2015,[1] leaving a lasting and profound impact on women, families, communities, and healthcare workers.[2] The care received by women and their families immediately after a stillbirth, and in the days and months that follow, however, is inconsistent and often deficient.[3] The 2016 Lancet Ending Preventable Stillbirth Series called for a 'global consensus on a package of care after a death in pregnancy or childbirth… for the affected family, community, and caregiver in all settings'.[4]

Recent systematic reviews of care after stillbirth[5,6] have shown many comparable findings across low, middle, and high-income settings in the experiences of women, their families, and healthcare workers. Women experience a broad range of manifestations of grief which may not be recognised by healthcare workers, or by their communities. This lack of recognition exacerbates psychological symptoms as well as stigma, blame, devaluation, and loss of social status.[2,3] Conversely, positive attitudes and support during bereavement from health care workers, family, and communities, can improve bereavement experience.

High quality care can moderate both immediate and long-term negative outcomes.[2] National guidelines already exist in some settings to guide health care workers and organisations responsible for providing care to bereaved women after stillbirth.[7,8] However, evidence for best practice is limited in most settings, especially low- and middle-income countries (LMICs) where the burden is greatest.[1] This lack of relevant evidence has hindered progress towards concerted global action. The same fatalism that has plagued stillbirth prevention for decades,[1] seems to also lead to a lack of recognition of loss that has impeded agreement on bereavement care.

The aim of this study was to develop a global consensus on a set of feasible and evidence-based core principles for bereavement care after stillbirth, to meet the milestones set by the Lancet in 2016.

## Materials and methods

A modified policy Delphi methodology[9] was used to establish a global consensus on principles for a package of bereavement care following stillbirth for women and their families. We gathered the opinions of international stakeholders and healthcare workers experienced in providing bereavement care, over five sequential rounds. During a 12-month period, two expert stakeholder meetings and three web-based surveys were conducted (figure 1).

### Round One

An expert stakeholder meeting was held by the research team at the International Stillbirth Alliance (ISA) conference in September 2017 (Cork, Ireland). An international panel of clinical and academic experts were identified through the International Stillbirth Alliance (ISA) global network and invited to join a pre-conference workshop. Participants (n=23) were asked to discuss evidence-based themes extracted from two systematic reviews of care after stillbirth, one in high-income countries (HICs),[6] and one in low- and middle-income countries (LMICs)[5] (table 1).

Participants discussed four key topic areas derived from a systematic review[6] in groups of five to six: overarching principles; diagnosis, delivery and postnatal care; follow up and support; and healthcare workers (Supplementary information 1 – Round 1 topic guide). A member of the research team facilitated each group. Discussions were documented in note form on the same day. Thematic analysis identified a list of core statements about care after stillbirth, which was used for the webbased survey in round two (table 2).

### Round Two

The group of stakeholders who attended the consensus workshop, including the research team, were invited to complete an anonymous web-based survey (Supplementary information 2- Round 2 survey) hosted by 'Survey Monkey'.[10] Respondents were asked to rank the importance of each statement generated in round one, from 1 to 10. They were also

asked to provide feedback and comments on the statements, to ensure they accurately reflected the discussions from the initial workshop, and to help integrate similar themes. Mean scores were calculated for each statement.

**Round Three**

The principles resulting from round two were used as the basis for a global web-based survey, targeted at health-care workers in a wide range of settings (Supplementary information 3 - Round 3 Survey). The online survey was managed using 'Survey Monkey'[10] and was distributed with an introductory email containing a link to the questionnaire. The intent was to distribute the survey to as wide a range of healthcare workers as possible using multiple avenues that included personal contacts, professional bodies, mailing lists for formal and informal networks including the ISA, Healthy Newborn Network (HNN), and Health Information for All (HIFA). Particular efforts were made to include LMIC respondents by targeting personal contacts in these settings. The survey was piloted by the research team to check usability. The survey remained open from April to May 2018. Responses were analysed using descriptive statistics and histograms.

Participants were asked to rank the importance of each principle using a 9-point Likert scale from 1 (not at all important) to 9 (critically important), and encouraged to leave comments on each principle, including barriers to implementation in their setting.

There are no routinely agreed criteria for establishing consensus in Delphi surveys, with a wide variation in methodology reported.[11] For this project it had been agreed in advance that consensus would be established for each principle if over 70% of participants scored the principle as critical (score 7-9) and fewer than 15% scored the principle as unimportant (score 1-3). Conversely, principles would be excluded if 70% of participants scored the principle as unimportant (score 1-3) and fewer than 15% scored the principle as critical (7-9). These criteria have successfully been used in other consensus studies.[12]

Barriers to implementation for each principle were analysed with framework analysis based on the WHO Health Systems Framework.[13]

Participants were also asked to select the top three principles they felt were most important, to help inform priorities for implementation.

**Round Four**

A second expert stakeholder meeting was held at the International Society for the Study and Prevention of Perinatal and Infant Death and International Stillbirth Alliance (ISPID-ISA) conference in June 2018 (Glasgow, UK). The same international stakeholders from round one were invited to join a pre-conference workshop, along with other experts nominated during the previous three rounds.

The findings of the global survey were presented at the workshop. Participants worked in small groups to discuss the results of the survey and the wording of the principles. Two members of the research team were assigned to each group to facilitate and document discussions. After the workshop, the research team met to review the discussions and produce the final amended principles.

**Round Five**

The final round of the consensus involved a web-based survey (Supplementary information 4- Round 5 survey) sent out to all participants of the global survey in round three, and attendees of either bereavement consensus workshop. The purpose was to present the amended principles and gain consensus on the amendments made in round four. Respondents were asked to rank each principle using a Likert scale, as in round two, with the same criteria for establishing consensus. Three reminder emails were sent to email addresses voluntarily provided by participants in previous rounds of the consensus process.

## Results

### Round One

The expert stakeholder group (n=23) included obstetricians (n=6, 26%), midwives (n=4, 17%) researchers (n=10, 43%), a pathologist (n=1, 4%), neonatologist (n=1, 4%), and a chaplain (n=1, 4%), some of whom were also bereaved parents. A total of 43 evidence-based themes were considered by the group (table 1). Ten statements were generated for round two (table 2).

### Round Two

A total of 19 (83%) participants responded to the web-based survey. Scoring of the statements ranged from 8.4 to 9.8 out of 10 demonstrating that each was considered important by participants.

No additional topic areas were suggested by the participants beyond the previously identified ten statements.

Comments from respondents identified areas of ambiguity in wording, and areas for clarification. The core statements were adjusted with minor wording changes in response to comments: for example, to reflect ‘parents’ rather than ‘women’. The number of statements were reduced from ten to nine (table 2), as two were reported by respondents as having complementary meaning (‘Healthcare workers should acknowledge the breadth of grief associated with stillbirth, across all settings’ and ‘Healthcare workers should acknowledge that grieving is a natural response to the loss of a baby and offer appropriate emotional support to all women’) that could be combined into one principle. General comments and responses informed the design of the global survey in the next round.

### Round Three

The global survey received 236 responses, from 26 countries (figure 2). Most respondents identified themselves as midwives (46%), obstetrician/gynaecologists (23%), and nurses

(9%). The remaining respondents included psychologists, pathologists, public health specialists, researchers, and social workers.

Over half of participants (55%) had worked in their role within healthcare for more than 20 years, and 26% for 11-20 years. Most respondents were based in HICs (78%), whilst 22% of respondents worked in LMICs. Participants in Australia contributed 57% of total responses.

All nine principles met the previously agreed criteria for inclusion in the consensus (table 3). All principles were scored by more than 75% of participants as critical (7-9) and less than 2% of participants scored any of the principles as unimportant (1-3). All principles remained eligible for inclusion when scores were analysed separately by HICs and LMICs.

The score for public education about stillbirth scored the lowest of all the principles, both in HICs and LMICs, but still met criteria for inclusion in the consensus. Respondents commented that this principle should be more specific to stillbirth bereavement care, rather than education about stillbirth in general. This was taken into account in round 4 when principles were revised.

Overall, the principles were rated very similarly by participants in LMICs and HICs (table 3). Respondents from HICs rated respectful care and emotional support, information about management options and delivery, and investigation of cause of stillbirth, higher than respondents from LMICs. LMIC respondents rated postnatal care and follow up, and information about future reproductive health more highly than HICs.

When respondents were asked to rank their top three priorities (figure 3), training of healthcare staff in the care of bereaved parents was considered the most important in both LMICs and HICs and was included in the top three principles by 65.2% of respondents overall (61.7% LMIC, 66.1% HIC). This was followed by investigation to provide an explanation to parents for the loss of their baby

(43.8% overall, 42.6% LMICs, 44.1% HICs). Public education about stillbirth, whilst having received the lowest importance score, was the fourth most likely principles to be ranked as a top priority, supporting the need to revise its wording rather than omit.

There was more variation in the prioritisation of other principles. For example, provision of respectful maternity care was included by 59.6% of respondents in LMICs, but only 34.5% in HICs. Conversely, provision of information on management options and delivery was included by 35.6% of HIC respondents, but only 12.8% of LMIC respondents. Information about future pregnancy was considered important by 21.3% of LMIC respondents, but only 6.2% of HIC respondents, giving it the lowest score overall.

With regards to barriers to implementation (table 4), respondents from HICs reported fewer barriers overall and were more likely to comment 'no barriers' or 'this is already done in my healthcare facility'. Both HIC and LMIC respondents identified barriers in each of the six areas, many of which represented similar themes; for example, lack of funding and resources for staff training, cultural issues including taboo and stigma, and the need for clear clinical guidelines.

**Round 4**

The second consensus workshop at the 2018 ISPID-ISA conference in Glasgow was attended by 30 participants including obstetricians (n=10, 33%), midwives (n=5, 17%) researchers (n=11, 37%), representatives of charitable organisations (n=3, 10%) and a neonatologist (n=1, 4%), some of whom were also bereaved parents. Of the nine countries represented, two were LMICs (Ghana and Georgia). The results of the global survey from round three were presented and discussed.

Two principles concerning postnatal care and follow up ('All parents should be offered appropriate postnatal care addressing physical and psychological needs' and 'Bereaved parents should be given adequate information before discharge from healthcare setting, including a lead professional contact in the follow-up period') were combined as they were

considered by the workshop participants to have significant overlap. Wording was adjusted to be inclusive of women, partners, their families and the stillborn baby. The workshop produced eight final principles (table 5) which retain the sense and importance of the statements included in the global survey of round three, with improved wording and more concise meaning, including active verbs to prompt action in response to the Lancet call.

**Round 5**

The response rate for this round was 54% (143/267). No objections were raised by participants to any of the eight principles, which all fulfilled the criteria for inclusion in the final list (table 5).

## Discussion

Widespread recognition of the need for quality bereavement care after stillbirth to reduce stigma and preventable harm to parents, their families, and their communities, made this consensus process a timely exercise to meet the milestones set by the Lancet.[4] Rounds one and two of the Delphi process used the results of systematic reviews in LMICs and HICs, along with the experience of expert stakeholders, to develop evidence-based principles for bereavement care. These were revised and refined throughout the multi-round consensus process with input from healthcare workers and other professionals involved in stillbirth care from around the world. The response to the global survey, with 236 participants from 26 countries, demonstrates the wide reach and level of interest in this topic. The enthusiastic response rate from Australia may reflect significant recent stillbirth awareness work through a nationally funded program[14]. Encouragingly, overall almost one in four responses were from LMICs, representing 18 different countries. There is a continuing need to understand the challenges to quality bereavement care in low-resource settings in which the majority of stillbirths occur globally.[1,15]

In some HICs, such as the UK[7] and Ireland[8] national guidelines for bereavement care after stillbirth do exist, but may be too resource intensive to be implemented in other settings. A comprehensive review of evidence for respectful and supportive bereavement care by the Perinatal Society of Australia and New Zealand, and the Australian Stillbirth Centre of Research Excellence[14] describes many themes which are similar to the principles developed in this study, whilst acknowledging that evidence for best practice is limited, particularly in LMICs. The RESPECT consensus study has combined this limited evidence with intelligence from global experts and interested health care workers to advance our understanding.

The final eight bereavement care principles all met predefined criteria for inclusion in the consensus, with a high level of concurrence between HICs and LMICs in round three. The differences that were evident between HICs and LMICs may reflect priorities for implementation or the standards of care that are already in place in each setting, as well as socio-cultural and health system differences. Using the WHO framework[13] to explore barriers provided context to the scoring and prioritisation results. For example, provision of respectful maternity care was ranked as a top priority by more than half of respondents in LMICs, but only one in three in HICs. Many respondents in HICs commented in the barriers section of the global survey that this principle was already routinely enacted in their setting. This apparent disparity between settings, therefore, likely reflects a difference in perceptions about the health systems rather than the importance of the principle itself.

In addition to the development of the final list of principles, the multi-stage consensus process itself was useful for understanding different contexts, and the way they impact on provision of bereavement care. This understanding will help tailor implementation approaches to various settings and country-specific action plans. For example, the principle concerning future reproductive health and family planning had low ranking in round two compared to other principles. It also represented one of the biggest differences between

LMICs and HICs in both the scoring and prioritisation exercises of round three. This is concordant with the findings from a systematic review of care after stillbirth in LMICs, where desire for more information on future pregnancy was mentioned often by women and their partners.[5] In a systematic review in HICs[6] the need for more information about future reproductive health did not feature in the narratives by bereaved parents, possibly because in such settings it is commonly addressed at medical follow-up. To address this disparity, in low-resource settings, where follow up is difficult to arrange, more information may need to be imparted in the immediate postpartum period.

These two examples are important reminders that it is necessary to capture perspectives and opinions from specific settings in both LMICs and HICs before prioritising any interventions for global implementation.

The barriers and facilitators captured by the consensus process provide additional useful insight into implementation of the bereavement care principles. Many comments were similar across settings, despite different baselines of care provision. Staff training was a major factor in all settings, as well as a desire for clear localised guidelines. Implementation may need to start with more general efforts to reduce stigma, train healthcare workers in emotional care, and provide respectful care to all women accessing maternity services. Other targeted aspects of best practice will need to follow, such as improving stillbirth investigation and offering birth options including analgesia. Conversely, targeting specific initiatives to high risk groups first, such as families who have experienced a previous loss, or women with poor social support, may make best use of resources in some settings, with more general expansion possible as resources become available.

The major strength of this project is the size, breadth and depth of response to the global survey. There were multiple rounds in the overall process, and involvement of international experts, with ample opportunity for objections, refinements, and identification of barriers and facilitators.

The spread of settings of response to the global survey is a limitation. South America, francophone Africa and the Middle East were under-represented whereas Australia was over-represented. The experts attending the workshops were predominantly female and Caucasian from HICs. The survey was not translated to languages other than English. Ongoing efforts are needed to engage healthcare workers from all settings, to achieve an even wider consensus.

This work sought to develop global consensus on a set of feasible, evidence-based, core principles from a healthcare perspective. Some participants, however, including researchers and workshop participants, have also had personal or family experience of stillbirth or neonatal death. This lived-in experience adds another dimension to the results of the consensus process, as it is important for the principles to be parent-centred. A next important step will be to incorporate the voice of bereaved parents from around the globe formally and widely. This could be facilitated by communicating the findings from this study and the challenge will be to elicit opinions from LMIC communities who may be more difficult to reach with methods such as online surveys.

Even though the consensus process was based on systematic reviews that captured published research from both LMICs and HICs, there remains an urgent need for further primary research in LMIC settings, to ensure that recommendations are appropriate for each setting, globally. This should also include well documented pilots and implementation research to improve the evidence base for the design of bereavement care packages in different contexts. Establishing a community of practice, particularly for those in LMIC settings, may be highly beneficial.

It is essential, for successful implementation, that stillbirth bereavement care is incorporated into the normative guidelines of global agencies such as WHO and UNICEF who are responsible for setting standards of care for LMICs, as well as inclusion in other relevant initiatives such as the Every Newborn Action Plan[16], in order to gain political momentum to improve bereavement care. Each LMIC can adapt guidance and tools from these sources for their own context.

Finally, it is important to acknowledge the impact of all perinatal loss on a global scale and the need for bereavement care not limited to those experiencing stillbirth. Although this study was focussed on stillbirth, it would be useful to consider how these principles may overlap and be applicable to other aspects of perinatal bereavement care, including neonatal death.

This consensus process has produced eight core principles for bereavement care after stillbirth, with contributions from a wide range of experts and healthcare workers actively involved in frontline care. More work is needed to involve the voices of parents globally and explore the best way to implement care packages for each principle in a variety of settings. Women and their families continue to experience stillbirth every day, however, and it is time to recognise the need for basic bereavement care now and start ameliorating the impact of stillbirth globally.

**Author contributions:** DS and CSh conceived the study. DS is lead author and guarantor of data. All authors contributed to design of the study and interpretation of findings. CSh, AM, DB, ML, CSt and DS organised and ran the workshops and surveys. The RESPECT group contributed to workshops. CSh, AM and DS analysed the data. CSh was responsible for writing the first draft and all authors contributed to finalising the manuscript.

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**Figures and Tables**

## Table 1. Themes from systematic reviews of care after stillbirth in low, middle, and high-income settings

| Thematic sentences from systematic review, low- and middleincome countries (LMICs)[5]. | Thematic sentences from systematic review, high-income countries (HICs)[6]. | |
|---|---|---|
| **Themes common to both reviews** | | |
| Across all settings, women experience multiple manifestations of grief, which the healthcare community and wider society often fails to recognise | Parents have a range of emotions and reactions because stillbirth is a life changing event | Emotional support and acknowledging the birth and death of a baby is an important part of bereavement care |
| Positive community support, as opposed to stigmatisation and blame, can improve bereavement experience. | Parents wish for increased awareness and acknowledgement of stillbirth | |
| Women and staff believe that specialised bereavement care is important | Parents with a baby who died in-utero may feel that their care is not appropriately prioritised by staff | |
| Understanding the causes of stillbirth and supporting proper investigation will help to reduce stigma. | Long delays and inconclusive results can cause distress to parents | There are many factors which influence parents decision whether to have a postmortem |
| Women value supportive family presence throughout care | Parents want privacy not abandonment | |
| Awareness of, and support for, different coping mechanisms, as culturally and individually appropriate, can assist with the grieving process. | Spending time and making memories with their baby should be an option that is supported and offered more than once | |
| Availability of timely and culturally appropriate psychological support is desired. | Support groups are helpful for many parents | |
| Knowledge and information about stillbirth will empower women to take control of their own health | Support and Information from staff may help parents who feel emotionally unprepared for a vaginal birth | To be involved in decision making parents appreciate being given options and the time to consider them |
| | Pain relief options should be fully discussed with parents | Staff should support parents to express their concerns |
| | Clear, easily understandable and structured information given sensitively at appropriate times, helps parents through their experience | |
| Women value follow-up care and advice to help them return to health. | Continuity of care and carer is important to parents | |
| | Continuity of care is important to staff | |
| | Parents should be supplied with information about what to expect postnatally | |
| | A debriefing and follow-up appointment can help resolve uncertainty | |
| Adequately developed health systems are best equipped to provide respectful care. | Parents would appreciate a healthcare system ready to provide emotional support following birth and discharge from hospital | There are challenges that may prevent staff from providing effective bereavement care; Emotion, Knowledge and System based |
| Comprehensive staff training and support systems for staff are prerequisite to improving care. | Behaviours and actions of staff can have a memorable impact on parents | Staff want improved training and a supportive working environment |
| | Research and multi-professional training is important for all staff to improve standards of bereavement care | |
| | Parents want improved training so that staff can provide tailored discussions and written information to help them make informed decisions about post-mortem and funeral arrangements | |
| | Verbal and non-verbal communication skills are important | |
| | Experience and knowledge may ease the provision of bereavement care but can increase the emotional burden felt by staff | |
| **Themes found only in LMIC review** | **Themes found only in HIC review** | |
| Cultural differences and beliefs can lead to devaluation and stigmatisation of women and babies. | Fathers may have different needs to mothers; they want to be involved in decision making and often focus on practical tasks | |
| Women want information, advice and individualised discussions about future pregnancies. | Parents may regret certain decisions made regarding Post-Mortem and funeral arrangements | Clear care pathways are required at the interface between primary and secondary care |
| | Providing parents with information, enabling them to be actively involved in decision making, is a staff priority | |

## Table 2. Iterations of principles through rounds 1-5

| Round 1 | Rounds 2&3 | Rounds 4&5 |
|---|---|---|
| Public education about stillbirth should be promoted to raise awareness. | Public education about stillbirth should be promoted to raise awareness. | **Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities.** |
| Staff should provide respectful care to bereaved women, in accordance with WHO statement on respectful maternity care. | Staff should provide respectful care to bereaved women, in accordance with WHO statement on respectful maternity care. | **Provide respectful maternity care to bereaved women, their families and their babies.** |
| Parents should be provided with clear and understandable information about management options and delivery | Parents should be provided with clear and understandable information about management options and delivery | **Support women and families to make shared, informed and supported decisions about birth options.** |
| An effort should be made to investigate and provide an explanation to parents for the loss of their baby, within resources available. | Every effort should be made to investigate and provide an explanation to parents for the loss of their baby, within resources available. | **Make every effort to investigate and identify contributory factors, to provide an acceptable explanation to women and families for the death of their baby.** |
| Healthcare workers should acknowledge the breadth of grief associated with stillbirth, across all settings. | Healthcare workers should acknowledge the breadth of grief associated with stillbirth and offer appropriate emotional support. | **Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment.** |
| Healthcare workers should acknowledge that grieving is a natural response to the loss of a baby and offer appropriate emotional support to all women. | | |
| All parents need appropriate postnatal care addressing physical and psychological needs, and follow up encounters to provide information and assess wellbeing. | All parents should be offered appropriate postnatal care addressing physical and psychological needs. | **Offer appropriate information and postnatal care to address physical, practical and psychological needs, including a point of contact for ongoing support.** |
| Bereaved parents should be given adequate information before discharge from healthcare setting, including a single point of contact in the follow-up period. | Bereaved parents should be given adequate information before discharge from healthcare setting, including a lead professional contact in the follow-up period. | |
| Women should receive adequate information about their future reproductive health, including family planning if desired. | Parents should receive information about their future reproductive health, including family planning if desired. | **Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow up.** |

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| Healthcare staff should be offered basic training in the care of bereaved parents, including evidence-based principles of care and management, and communication skills, and be aware of processes/guidelines in their own unit. | Healthcare staff should be offered basic training in the care of bereaved parents, including evidence-based principles of care and management, and communication skills, and be aware of processes/guidelines in their own unit. | **Enable the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the healthcare team.** |

## Table 3: Principle statements in Round 3, demonstrating consensus criteria. (1-3 unimportant, 7-9 critical)

| Principle | Overall | | | LMIC | | | HIC | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1-3 (%) | 4-6 (%) | 7-9 (%) | 1-3 (%) | 4-6 (%) | 7-9 (%) | 1-3 (%) | 4-6 (%) | 7-9 (%) |
| All parents should be offered appropriate postnatal care addressing physical and psychological needs. | 0.0 | 4.5 | **95.5** | 0.0 | 2.1 | **97.9** | 0.0 | 5.1 | **94.9** |
| Healthcare staff should be offered basic training in the care of bereaved parents, including evidence-based principles of care and management, and communication skills, and be aware of processes/guidelines in their own unit. | 0.0 | 5.4 | **94.6** | 0.0 | 6.4 | **93.6** | 0.0 | 5.1 | **94.9** |
| Parents should be provided with clear and understandable information about management options and delivery. | 0.9 | 4.9 | **94.2** | 0.0 | 8.5 | **91.5** | 1.1 | 4.0 | **94.9** |
| Healthcare workers should acknowledge the breadth of grief associated with stillbirth and offer appropriate emotional support. | 0.0 | 5.8 | **94.2** | 0.0 | 10.6 | **89.4** | 0.0 | 4.5 | **95.5** |
| Staff should provide respectful care to bereaved women, in accordance with WHO statement on respectful maternity care. | 0.0 | 6.3 | **93.8** | 0.0 | 12.8 | **87.2** | 0.0 | 4.5 | **95.5** |
| Bereaved parents should be given adequate information before discharge from healthcare setting, including a lead professional contact in the follow-up period. | 0.9 | 6.3 | **92.9** | 0.0 | 6.4 | **93.6** | 1.1 | 5.6 | **93.2** |
| Every effort should be made to investigate and provide an explanation to parents for the loss of their baby, within resources available. | 0.5 | 8.0 | **91.5** | 0.0 | 10.6 | **89.4** | 0.6 | 7.3 | **92.1** |
| Parents should receive information about their future reproductive health, including family planning if desired. | 0.5 | 9.4 | **90.2** | 0.0 | 4.3 | **95.7** | 0.6 | 10.7 | **88.7** |
| Public education about stillbirth should be promoted to raise awareness. | 1.3 | 22.2 | **76.3** | 0.0 | 19.1 | **80.9** | 1.7 | 23.2 | **75.1** |

## Table 4: Barriers and Facilitators to implementation of care based on 9 principles (round 3)

| Barriers | LMIC | HIC |
|---|---|---|
| Leadership and Governance | • Lack of supervision of healthcare workers to ensure quality of care provided. | • Lack of consensus amongst care providers leading to inconsistency.<br>• Lack of guidance on monitoring of the quality of care provided. |
| Healthcare financing | • Costs of care provision and shortage of resources for separate facilities, or post-mortem. | • Costs of investigations including postmortem for cause of death.<br>• Lack of funding for training. |
| | • Lack of funding and resources for training. | • Lack of funding for specialist bereavement teams. |
| Health workforce | • Inadequate numbers of healthcare workers.<br>• Lack of workforce skills and knowledge; need for training.<br>• Staff demotivation.<br>• Resistance of healthcare workers to change.<br>• Lack of support for healthcare workers<br>• Burnout from high perinatal mortality rates. | • High levels of stress and workload amongst healthcare workers.<br>• Limited awareness and recognition of importance of mental health issues.<br>• Lack of training opportunities for staff, including in communication skills. |
| Medical products, technologies | • Appropriate information for families unavailable in local languages.<br>• No access to post-mortem. | • Limited availability of appropriate written information for families.<br>• Limited resources for investigation and post-mortem in some settings. |
| Information and research | • Community myths and misconceptions about stillbirth.<br>• Lack of public knowledge about stillbirth.<br>• Need for appropriate localised management guidelines. | • Fear of provoking anxiety to women by public education about stillbirth.<br>• Lack of evidence base to support training, or on the impact of interventions. |

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| Service delivery | • High volume of workload, including emergencies, and overcrowded healthcare facilities, leading to prioritisation of physical over psychological wellbeing<br>• Sociocultural issues and beliefs about stillbirth eg. death not discussed, unborn baby not recognised.<br>• Stigma and societal negative attitudes<br>• Facilities including space and confidentiality<br>• Lack of access to antenatal care | • Busy clinical areas and wards, limited time for patient care.<br>• Cultural issues- not wanting to talk about loss, religious beliefs, taboos.<br>• Stigma<br>• Medicalisation may increase intervention rates and neglect psychological care. Lack of facilities eg. separate bereavement suite.<br>• Lack of access to psychological services.<br>• Lack of clinical pathways or local guidelines |
| **Facilitators** | **LMIC** | **HIC** |
| | • Public education on stillbirth via social media, radio and TV<br>• Use of community health workers and village health communities, including opinion leaders or religious leaders.<br>• Incorporation of education on stillbirth into antenatal care<br>• Inclusion in 'minimum service delivery standards for Maternal and Newborn Care', and/or neonatal death audits.<br>• Training for all healthcare staff.<br>• Development of care pathways or flow charts for easy reference.<br>• Women's groups and peer support groups for emotional support from other bereaved mothers. | • Public education to reduce stigma via conventional and social media.<br>• Inclusion in antenatal care and birth classes.<br>• Linking with primary care, including postnatal home visits.<br>• Provision of bereavement suites, with designated team, space and outreach professionals.<br>• Training for all healthcare staff.<br>• Development of clear care package<br>• Individualisation of care- no 'one size fits all'.<br>• Support groups eg. SANDS in the UK, and peer support for emotional wellbeing. |

## Table 5: Final principles for global consensus

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| 1 | Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities. |
| 2 | Provide respectful maternity care to bereaved women, their families and their babies. |
| 3 | Support women and families to make shared, informed and supported decisions about birth options. |
| 4 | Make every effort to investigate and identify contributory factors, to provide an acceptable explanation to women and families for the death of their baby. |
| 5 | Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment. |
| 6 | Offer appropriate information and postnatal care to address physical, practical and psychological needs, including a point of contact for ongoing support. |
| 7 | Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow up. |
| 8 | Enable the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the healthcare team. |